

Thinking Ahead

There's so much to think about while you're pregnant. As you plan, take a minute to look ahead. At the hospital, your new baby will be tested – screened – for a variety of factors that may affect his or her health and development. You will not have to pay for any of these screenings. All conditions identified through these screenings can be treated if found early. We want your baby to get the best start possible, and these screenings are the first step.



Family Health Information Line

If you need more information about any of the newborn screening services or programs described in this guide, call the Family Health Information Line, toll-free, at 1-800-942-7434, weekdays from 8:30am to 4:30pm. Our team speaks English and Spanish.

MAKE HEALTH PART OF YOUR FAMILY

RHODE ISLAND DEPARTMENT OF HEALTH

Newborn Screening and Services

What you need to know
before you have your baby.





Newborn Blood Screening

Before you and your baby go home from the hospital, a few drops of blood will be taken from your baby's heel. This blood is used to screen for several serious conditions (see the insert for a list of the conditions for which babies are tested). The results will be reported to your baby's doctor, who will share them with you. Newborn blood screening is required by law. Blood samples are stored until your baby reaches adulthood. To refuse, you must sign a waiver stating that you understand the risk of not having the test done.

Screening for other conditions not on the list is available for a fee through other labs.

If you would like more information about additional testing, call the Family Health Information Line at **1-800-942-7434**, weekdays from 8:30am to 4:30pm.

Newborn Hearing Screening

Babies learn from the time they are born, and one of the ways they learn is through hearing. Newborn hearing screening can detect possible hearing loss in the first days of your baby's life. During your baby's stay in the nursery, a small microphone is put in your baby's ear to measure how the ear responds to soft sounds. The test takes 10 to 15 minutes and is not painful. If the results are unclear, the test may need to be repeated. The Rhode Island Hearing Assessment Program will contact you if more tests are needed.



Family Outreach Program

Like you, we want your baby to get off to a good start. While you and your baby are in the hospital, a nurse will review your pregnancy and delivery records. They will look to see if there are any reasons your baby's development could be delayed. Based on this review, the nurse may refer you to the Family Outreach Program, a home visiting program for families with newborns and young children at no cost to the family.

Family Outreach offers information and help with many of the challenges of bringing baby home, from breastfeeding support to making your home safe for your baby.

The program offers information on how to care for your baby, including topics such as breastfeeding and nutrition, when to call your baby's doctor, and how to make your home safe for your baby. Home visitors provide support and link you to resources and services in your community. While you are in the hospital, a nurse from the Family Outreach Program may stop in to tell you more about it, or someone may call you after you leave the hospital to schedule a home visit.

KIDSNET

KIDSNET is the Rhode Island information system that helps families and doctors make sure that children receive complete preventive health care. All babies born in Rhode Island have health information included in KIDSNET. As your baby grows, your doctor and others will add your child's immunizations and information from the following health screenings: developmental assessment, newborn hearing, newborn blood screening, and lead screening. Information from your baby's birth certificate and from the Family Outreach, Early Intervention, and WIC Programs is also included.

KIDSNET is used to remind families and doctors when immunizations, lead screenings, and other services are needed. If your child has been to different doctors, KIDSNET will keep track of all of his or her immunizations in one place. KIDSNET also helps to see whether all Rhode Island children are getting the care they need.

KIDSNET information is confidential and is protected under State and Federal privacy laws. Only the Health Department, doctors, nurses, and other approved professionals such as school nurses or the Head Start Program can see KIDSNET information. You have the right to restrict who can see your child's information. For more details, call KIDSNET at **401-222-4220**, weekdays from 8:30am to 4:00pm.



Congratulations!

Congratulations on the birth of your baby! This guide explains several early screening tests and services that Rhode Island offers for newborns. Before leaving the hospital, your baby will have these screening tests to detect serious conditions that may affect his or her health and development. All conditions identified through these screenings can be treated if found early. You do not have to pay for any of these screenings.



Family Health Information Line

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MAKE HE[♥]ALTH PART OF YOUR FAMILY

RHODE ISLAND DEPARTMENT OF HEALTH

Newborn Screening and Services

A guide to tests, screenings,
and programs for newborns.





Newborn Blood Screening

Before your baby leaves the hospital, a few drops of blood will be taken from your baby's heel. The blood will be tested for metabolic (how the body digests food), endocrine (controls many body functions) and hemoglobin (blood) conditions (refer to insert for more details about the conditions). Newborn blood screening is required by law. Blood samples are stored until your baby reaches adulthood. To refuse, you must sign a waiver stating that you understand the risk of not having the test done.

The newborn blood screening should be done when your baby is at least 24 hours old. If your baby leaves the hospital before this time, you will have to bring your baby back for the test. Sometimes, a test may need to be repeated. This does not necessarily mean that your baby has a condition. If your baby's test needs to be repeated, a doctor or nurse will call and tell you. The test needs to be repeated as soon as possible. It is best to do this at the hospital where your baby was born, but you can go to the lab at any maternity hospital in Rhode Island.

Results from these tests are reported to your baby's doctor. Tests are available for many conditions beyond those included in Rhode Island's Newborn Screening Program. These additional tests are available for a fee through other labs. If you would like to have your baby receive additional testing, speak with a doctor or nurse while you are in the hospital about the tests and where you can get them done.

Newborn Hearing Screening

During your hospital stay, your baby's hearing will be screened to measure how the ear responds to soft sounds. A small microphone is put in your baby's ear. The screening takes 10 to 15 minutes and does not hurt. If the results are not clear the test may need to be repeated. If this is needed, the Rhode Island Hearing Assessment Program will contact you. Bring your baby back to the hospital for the repeat test as soon as possible.

If the screening test shows that your baby might have hearing loss, or your baby has any other risk factors for hearing loss, the Hearing Assessment Program will recommend that you take your baby to a hearing specialist (audiologist) for more testing at six months of age. You will receive a letter from the Program reminding you to make this appointment.

Family Outreach Program

While you and your baby are in the hospital, a nurse will review your pregnancy and delivery records. They will look to see if there are any reasons your baby's development could be delayed.

Family Outreach offers information and help with many of the challenges of bringing baby home, from breastfeeding support to making your home safe for your baby.

Based on the review of your records, the nurse may refer you to the Family Outreach Program, a home visiting program for families with newborns and young children at no cost to the family. The program offers information on how to care for your baby including topics such as breastfeeding and nutrition, when to call your baby's doctor, and how to make

your home safe for your baby. Home visitors provide support and link you to resources in your community that help you and your baby get off to a healthy start.

While you are in the hospital, a nurse from the Family Outreach Program may stop in to tell you more about it. If they don't see you while you are in the hospital, they may call you to schedule a home visit. If you are not offered a home visit but would like one, call the Family Health Information Line at **1-800-942-7434**, weekdays from 8:30am to 4:30pm.



Birth Defects Program

Babies identified with birth defects in the newborn period are included in the Birth Defect Information System at the Department of Health. The Birth Defects Program helps make sure that families and their children receive appropriate services and referrals. This information is also used to study patterns of birth defects. All information in the registry is confidential and is protected under State and Federal privacy laws.

KIDSNET

All babies born in Rhode Island are enrolled in KIDSNET, the Rhode Island information system that helps families and doctors make sure that children receive complete preventive health care.

KIDSNET contains information from your child's birth certificate and information such as your name, address, and your child's doctor. As your baby grows, your doctor and others will add your child's immunizations and information from the following health screenings: developmental assessment, newborn hearing, newborn blood screening, and lead screening. Information from the Family Outreach, Early Intervention, and WIC Programs is also in KIDSNET.

KIDSNET is used to remind families and doctors when immunizations, lead screenings, and other services are needed. If your child has been to different doctors, KIDSNET will keep track of all of his or her immunizations in one place. KIDSNET also helps to see whether all Rhode Island children are getting the care they need.

KIDSNET information is confidential and is protected under State and Federal privacy laws. Only the Health Department, doctors, nurses, and other approved professionals such as school nurses or the Head Start Program can see KIDSNET information. You have the right to see your child's information. If you feel the information is incorrect or incomplete, you have the right to ask that it be changed. You also have the right to restrict who can see your child's information. For details about how to do this, call KIDSNET at **401-222-4220**, weekdays from 8:30am to 4:00pm.



Baby is Home!

Now that you and your baby are home, we want you to know what happens following the screening tests that were done while your baby was in the hospital. You can get the results of these tests from your doctor.



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Newborn Screening and Services

A guide to test results, programs,
and follow-up for your baby.





Newborn Blood Screening

Your baby had a blood test in the hospital to check for metabolic (how the body digests food), endocrine (controls many body functions) and hemoglobin (blood) conditions (refer to insert for more details about the conditions). This blood sample will be stored until your baby reaches adulthood.

Sometimes this test needs to be repeated. This does not necessarily mean that your baby has a condition. If your baby's test needs to be repeated, a doctor or nurse will call and tell you. The repeat test should be done as soon as possible. It is best to have the repeat test done at the hospital where your baby was born, but you can go to the lab at any maternity hospital in Rhode Island. Results from these tests are reported to your baby's doctor. Tests are available for many conditions beyond those included in Rhode Island's Newborn Screening Program. These additional tests are available for a fee through other labs. If you would like to have your baby receive additional testing, talk to your baby's doctor.

Newborn Hearing Screening

In the hospital your baby's hearing was screened to measure how the ear responded to soft sounds. Sometimes the hearing screening needs to be repeated if the results are unclear. The Rhode Island Hearing Assessment Program will contact you if your baby needs to be retested. Bring your baby back to the hospital for the test as soon as possible.

If the test shows your baby might have hearing loss or your baby has risk factors for hearing loss, the Hearing Assessment Program will recommend that you take your baby to a hearing specialist (audiologist) for more testing.

If you have questions about your baby's hearing or test results, call the Hearing Assessment Program at **401-277-3700** voice/relay or **401-277-3701** TDD.

Your baby's doctor will continue to check your baby's hearing, speech, and language development along with other developmental milestones at each visit.

Family Outreach Program

While you and your baby were in the hospital, a nurse reviewed your pregnancy and delivery records. They looked to see if there were any reasons your baby's development could be delayed. Based on the review of your records, the nurse may have referred you to the Family Outreach Program.

The Family Outreach Program is a home visiting program for families with newborns and young children at no cost to the family. The program offers information on topics such as breastfeeding and nutrition, when to call you baby's doctor, and how to make your home safe for your baby. Home visitors provide support and link you to resources in your community that help you and your baby get off to a healthy start.

You may be offered a visit to have your baby's growth and development checked again at 6–8 months of age. The home visitor can help connect your baby to the Early Intervention Program or other early childhood programs if needed.

If you are interested in receiving a home visit and have not been offered one, please call the Family Health Information Line at **1-800-942-7434**, weekdays from 8:30am to 4:30pm.

Birth Defects Program

Babies identified with birth defects in the newborn period are included in a Birth Defects Information System at the Department of Health. The Program helps make sure that families and their children receive appropriate services and referrals. This information is also used to study patterns of birth defects. All information in the registry is confidential and is protected under state and federal privacy laws.

If you do not want your child's information entered into the Birth Defects Information System, you may either contact your child's doctor directly or call the Family Health Information Line at **1-800-942-7434**, weekdays from 8:30am to 4:30pm. You also have the right to restrict the release of information on your child from the Information System and to chose to not be contacted by the Birth Defects Program.

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Rhode Island screens babies for the following nine conditions and hearing loss. Many serious effects of these conditions can be prevented with early detection and treatment.

BIOTINIDASE DEFICIENCY

- » Babies with this condition cannot use a vitamin called biotin. This can cause babies to grow very slowly, and they can become mentally retarded.
- » This condition is treated with special medicine.

CONGENITAL ADRENAL HYPERPLASIA (CAH)

- » Babies with this condition cannot make enough of certain types of hormones.
- » This condition is treated with special medicine.

CONGENITAL HYPOTHYROIDISM

- » Babies with this condition do not make enough thyroid hormone. Without the right amount of this hormone, babies grow very slowly, and they can become mentally retarded.
- » This condition is treated with special medicine.

GALACTOSEMIA

- » Babies with this condition cannot use the sugars in milk, formula, and breast milk. If it is not treated, it can hurt the baby's eyes, liver, and brain.
- » This condition is treated with special formula and diet.

HOMOCYSTINURIA

- » Babies with this condition do not have enough of a chemical used in the liver. It can cause mental retardation and other health problems.
- » This condition is treated with a special diet.

MAPLE SYRUP URINE DISEASE (MSUD)

- » Babies with this condition cannot use parts of protein in milk and food. It can cause mental retardation and other health problems.
- » This condition is treated with a special diet.

MEDIUM CHAIN ACYL-COA DEHYDROGENASE (MCAD) DEFICIENCY

- » Babies with this condition cannot break down certain kinds of fat to use for energy. It can cause brain damage and other health problems.
- » This condition is treated with a special diet.

PHENYLKETONURIA (PKU)

- » Babies with PKU cannot use a certain part of protein found in milk and food. It can cause brain damage and learning problems.
- » PKU is treated with special formula and diet.

SICKLE CELL DISEASE

- » Sickie Cell Disease affects the baby's red blood cells. Babies with this condition can get very sick and even die from common infections.
- » This condition is treated early in an infant's life with daily antibiotics.

As testing methods improve, new conditions are added to the list. For the most current list of conditions that babies are tested for, visit our website at www.health.ri.gov/genetics/newborn.htm. Additional information about these conditions is available at www.savebabies.org. You can also call the Family Health Information Line at 1-800-942-7434, weekdays from 8:30am to 4:30pm.